

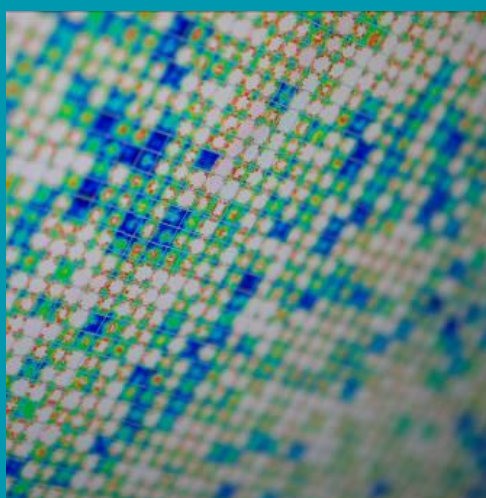
This response was submitted to the consultation held by the Nuffield Council on Bioethics on 'The linking and use of biological and health data' between 17 October 2013 and 10 January 2014. The views expressed are solely those of the respondent(s) and not those of the Council.



Diving into the Data Pool

Exploring public views about the way medical data is shared

Report from public event on 31 October 2013



Should it be easier for medical data to be shared to help research?

What are the implications for privacy, consent and the relationship between individuals and society?

Should NHS data be shared with industry?



Event details

Nowgen organised this event during Manchester Science Festival 2013 to explore how openly society wants medical data to be shared. It was held in the early evening at Manchester Museum and 45 members of the public attended (aged 14+).

This topic is being actively debated by researchers in different disciplines, but it is also important to explore public reactions. Three experts presented at this event to stimulate discussion and provide different perspectives (details opposite). Following the presentations, the audience were invited to discuss five key questions (details later in report). The audience was sat in small groups and each group had a facilitator to support discussion and make notes on key points raised. The public were also encouraged to write any comments they wanted recorded. Near the end of the event, people voted using interactive voting pads on three of the dilemmas.

This report reflects the views expressed by the public at this event. This report will be made available on the Nowgen website and will be passed onto the Nuffield Council on Bioethics enquiry into 'biological and health data' to respond to their consultation in late 2013 (<http://www.nuffieldbioethics.org/biological-and-health-data>).

Defining 'medical data' for this event

For the purposes of this event, we decided to focus on all types of data that would be recorded in the NHS, such as:

- Medical notes – from appointments in NHS, record of treatments and illnesses;
- Information from test results – blood tests, X-rays, etc;
- Data generated from taking part in research, such as clinical trials.

Other types of medical data were excluded, such as: shopping habits, self-monitoring (such as 'apps' that capture your sleep patterns, calorie intake, exercise routine), personal reporting through blogs, etc.

Programme

START	ACTIVITY
6.00	Dr Bella Starling (Director of Public Programmes at Nowgen) <ul style="list-style-type: none"> ○ Welcome introduce the topic and the format for the event
6.10	HOW BIG DATA CAN BE USED IN MEDICINE AND RESEARCH Professor Andy Brass, School of Computer Science, University of Manchester <ul style="list-style-type: none"> ○ Emphasising the benefits and power of linking large data sets
6.20	SOCIETY'S ROLE IN DECIDING HOW MEDICAL DATA IS USED/SHARED Dr Malcolm Oswald, Independent consultant specialising in healthcare information governance. <ul style="list-style-type: none"> ○ Highlighting some of the debates about sharing medical data and the need for careful governance
6.30	NUFFIELD COUNCIL ON BIOETHICS ENQUIRY Tom Finnegan, Research Officer, Nuffield Council on Bioethics <ul style="list-style-type: none"> ○ Overview on their enquiry and introduce issues included in public consultation
6.40	Questions or comments to speakers
6.55	DISCUSSION IN SMALL GROUPS (5-8 people per group) Facilitated discussion – groups asked to discuss questions from Nuffield Council on Bioethics' consultation about biodata how it could be used in medical research
7.15	Audience feedback Use voting pads and also share views from different groups
7.25	Closing comments
7.30	End



Background to the topic

We're in the era of 'big data' with billions of gigabytes of data added into the pool every day. This data revolution is transforming our world and we're all helping to generate it. Every time we search the internet, call, tweet, travel or buy anything, we're adding to this massive data pool. The public are often willing/keen to share data eg. Google, Facebook, image sharing, blogs, tweets, etc. All this data is valuable and it's used in many different ways. Data miners are looking for patterns and connections, trying to make discoveries and use the data to make predictions.

Big data sets are valuable to medical researchers to be able to develop new treatments and services to improve health. Researchers are keen to access different types of medical data, but how openly do the public want access to be permitted? What limits should be set?

Health records are increasingly being shared for medical research

The Health and Social Care Information Centre (HSCIC) was set up in 2013 and GP records have started to be transferred. People's name will be removed from this data, but their postcode and NHS number will be used to link records in a secure system. Access will be carefully controlled, but it will be shared within NHS and with private organisations.

DNA is increasingly being analysed alongside other health data

There are a number of large initiatives collecting DNA data, such as UK Biobank and recently, Genomics England Limited was launched to bring together 100,000 people's whole genome data and their medical records. The database they generate will be used by clinical teams, researchers and accessed by industry. In mid October 2013, they started to recruit the first 10,000 patients, as a pilot in Cambridge, to test procedures for the main study.

Public views about personal data being used in medical research?

In July 2013 the Wellcome Trust published findings from research into public attitudes on this topic. Their key findings were:

- Various benefits were identified such as allowing the Government to identify health needs and plan resources effectively, availability of vital medical data in an emergency. NHS use to monitor population health was generally regarded as very beneficial.
- Concerns highlighted included: data security, loss of privacy, including potential discrimination, unsolicited marketing and inability to correct inaccurate data. There was significant opposition to using data for commercial gain. There was a strong sense that such data would be confidential and sensitive and should not be shared outside the NHS. There were also worries about data linkage – eg. refusal of NHS treatment based on evidence of unhealthy diet from shopping records.

Questions explored at the event

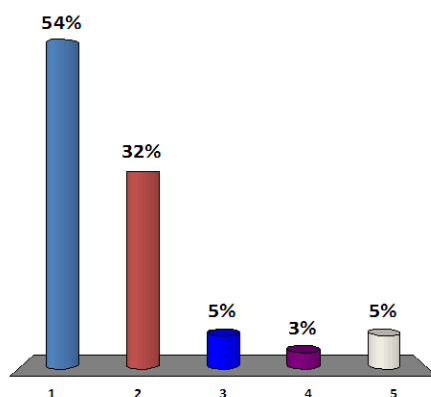
This report only includes people's reaction to the first three questions, as there was not time to explore the later questions in detail.

1. How do you feel about your medical data being added to a database to help develop medical services and research?
2. If researchers using this database identify individuals at high risk of an illness, should the patient get that feedback?
3. Do you support medical data being shared with researchers outside the NHS?
4. In your view, what are the main benefits from using large databases of medical data?
5. In your view, what are the main concerns from using large databases of medical data?

Question 1: How do you feel about your medical data being added to a database to help develop medical services and research?

The audience were supportive of this on the whole, with 86% saying that they were either very or quite supportive in the vote at the end of the event (see bar chart below). In discussion many people provided caveats and said this relied on the public individually consenting to this and the data being non-identifiable. The event explored how challenging it was to try to fully anonymise data, whilst allowing it to still be useful for research.

1. Very supportive
2. Quite supportive
3. Unsure
4. Quite concerned
5. Very concerned



One person said:

“Need more information on how and where stored, but in principle OK if handled correctly (ie. not shared with everyone and if shared outside of healthcare anonymise).”

Some people said they were worried about hackers and about the security of the data. They also asked questions about who it could be shared with and did not generally support the idea of the data moving outside of the NHS. A few people referred to the Data Protection Act and emphasised that there is a need for a well managed system. They said:

“The issue for me isn’t whether info is kept on me, but who by and the purpose for which it is being used. Data Protection Act (1998) – right to access info kept on you, who has it and why? Right to change it if proven incorrect. System required for public transparency and accountability. Including how safely secure that data is. Compensation if error occurs by offending party.”

A few expressed concern about the data being used negatively in the future. They asked about long term plans and wondered how data might be used in the future with new technologies. Some people said they were concerned that data sharing might jeopardise how honest people are with their doctors. One person said:

“More than happy, but what if used against me at a future date? Eg insurance or job interview – health questionnaire.”

A couple of people commented on the lack of publicity and the need for greater public debate on this topic. One comment was:

“Lack of communication to patients about data actually being shared. Unless GP actively telling patients or they are looking on the internet. They are not giving informed consent.”

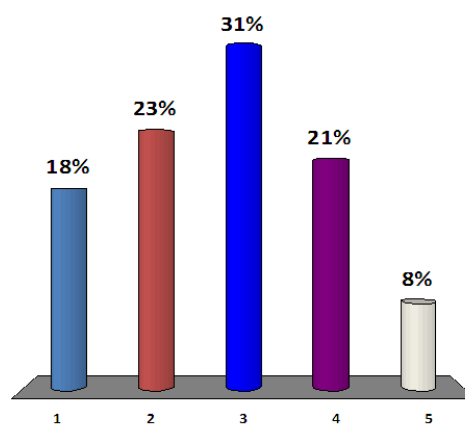
Question 2: If researchers using this database identify individuals at high risk of an illness, should the patient get that feedback?

This question received very mixed reactions and generated lots of discussion about the circumstances when providing feedback would be valuable. Many people felt it was down to the individual to decide whether they wanted this type of information. They made comments such as:

“Opt in/opt out option? Personal preference. Freedom of choice.”

The bar chart below shows the results from the votes made at the end of this event.

1. Very supportive
2. Quite supportive
3. Unsure
4. Quite concerned
5. Very concerned



In the discussion before the vote people expressed a number of worries, including concern about being given information about getting an illness that couldn't be cured/prevented/treated successfully. Many of them questioned how people would make sense of the risk information and who would have time to explain it to them.

A few people felt concerned about who else would find out, such as employers. One person said:

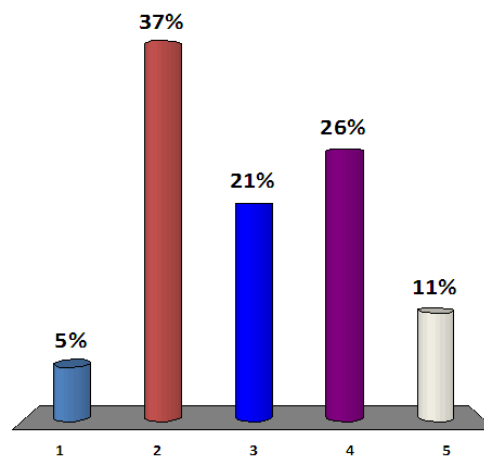
“Feedback to patients but who else will find out?”

A few people suggested that doctors got this risk information but not the patient, so doctors could be aware of people at risk, but the patient was not left overly concerned.

Question 3: Do you support medical data being shared with researchers outside the NHS?

This question received support from just over 40% of the audience, but the majority of people had some concerns about sharing the data outside the NHS. The bar chart below shows you the responses from the audience vote.

1. Very supportive
2. Quite supportive
3. Unsure
4. Quite concerned
5. Very concerned



In the group discussion, a few people commented on the benefits of pooling data sets and wanted to support the needs of research. Some mentioned that we should be thinking globally and bringing information together.

Alongside this support, people wanted to ensure that the public give consent to this and that the strong ethical and legal frameworks are used. Many people commented on supporting data sharing, provided the information did not reveal individual identities. One person said:

“Needs to be aggregated and anonymous.”

Some people questioned who benefits and was concerned about the idea of making profits. For example, one person stated:

“Not given to make a profit. This is not acceptable.”

Finally, as with the other questions, a few people in the audience commented on the need for individual consent to enable people to decide how widely they want their personal data to be shared.

Acknowledgements

Nowgen would like to thank the speakers, facilitators and audience for contributing to this interesting event. We would also like to thank Manchester Museum for kindly hosting this event.